RE: Operation Considerations

Operational Considerations:[1]

Operational requirements for obtaining and managing consent in an HIE ultimately depend on the patient consent model chosen for the HIE. Once the consent model has been chosen, however, there remain important tradeoffs to consider regarding consent collection, storage, transmission, and updating capability.

Two Ways to Collect Patient Consent in an HIE:

Directly from patients to the HIE:

- This collection method is advantageous because there is a lower burden placed on providers in terms of the additional time and cost of collecting the consent.

- A key challenge is to identify the patient and authenticate the consent.

- The same name-matching challenges that HIEs encounter when exchanging data with providers are also present in accepting consent directly from patients.

- The chosen consent model will influence the required level of authentication assurance.

Indirectly through providers:

- This collection method is advantageous because the HIE can rely on the provider to identify the patient and authenticate the consent, with the consent action being integrated into the patient encounter.

- Will the consent be provider-by-provider consent or global HIE multi-provider consent?

- Will the consent be stored by the provider only or sent to the HIE?

- Will the consent be the providers' assertion or will it require something from the patient, such as a paper signature, an electronic signature, or some other formal acknowledgement?

Other States' Consent Management Procedures:[2]

Delaware Health Information Exchange (DHIN):

- Providers must educate patients on DHIN and the Opt-out procedure.

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[1] Michael Berry Testimony for Data Security and Privacy Committee (July 17, 2012).
[2] Melissa M. Goldstein and Alison L. Rein, *Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis*, Appendix A (March 23, 2010).

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- DHIN supplies providers with talking points, sample privacy language, and confidentiality forms, and supplies a website for additional patient education.

- If a patient chooses to Opt-out of DHIN, he/she must have a form signed by a provider or a notary public (to verify the patient's identity) and then return it to DHIN.

Maryland - Chesapeake Regional Information System for Our Patients (CRISP):

- All patients are included in the system by default, but are given the opportunity to Opt-out.

- Patients can Opt-out by calling a toll-free number and requesting to be excluded.

Massachusetts e-Health Collaborative (MAeHC):

- Patients are given the opportunity to Opt-in to MAeHC when they visit a clinical entity for care.

- Through the Opt-in consent model, patients may choose to include all clinical data from each entity. Alternatively, patients may choose to include only a pre-defined set of data by selecting which entity's records to make available to the network.

- Signed patient consent forms must be uploaded from the provider's office to the exchange's database.

New York - Long Island Patient Information Exchange (LIPIX), HealtheLink (Buffalo), and Southern Tier Health Link (Binghamton) PCIP:

- Depending on the RHIO, there are two types of consent collection. The first type of consent collection is conducted by the provider organization at the point of service. The second type of consent collection is obtained through an RHIO multi-provider consent form, which can be accessed either at the point of service or online via the RHIO website.

- Patients can revoke their consent for participation in the exchange at any time. If consent is revoked, the existing data will remain in the exchange but will not be circulated unless required by law.

Rhode Island:

- Consent for data exchange is all or nothing. However, after consenting, patients have three options for their participation. The first option is that all providers involved in care are permitted to access the information. The second option is that only certain patient-selected provider organizations are authorized to access the information. The third option is the default setting, in which providers have temporary access to the information only in emergency situations.

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- The Rhode Island Quality Institute (RIQI) started training staff (prior to 2010) from participating provider and other organizations, including ambulatory and inpatient care settings, community-based organizations, and long-term care facilities, on effective ways to guide patients through the consent process.

- To enroll, patients complete an enrollment and authorization form specifically for the exchange. In addition, patients can enroll directly through the Current Care RI website, but need to call a hotline to indicate their provider preferences if they select participation option 2.

- Patients can revoke their consent for participation in the exchange at any time. If consent is revoked, the existing data will remain in the exchange but will not be circulated unless required by law.

- As of 2010, the Rhode Island Department of Human Services (RI DHS) was helping to offset the cost of administration by paying a $3 authentication fee for every participant that enrolled.

Washington - Health Record Banks (Four Pilot Programs):

- Washington's Health Record Banks are patient-controlled "data banks". In order to participate, patients must use web-based tools such as Microsoft HealthVault and Google Health to store their personal information in one location.

- Patients give consent by creating their own personalized accounts and then, using the HRB model, authorizing the release of their information to specific providers. At that point, copies of patient health information are transferred into the patient's HRB account. Patients have the opportunity to cancel their enrollment at any time.

Tennessee and Virginia - Carespark:

- Carespark has established an Opt-out with notice consent policy requiring patients to be at least minimally educated about the exchange before any data are collected.

- Carespark has employees who train provider organizations and give them educational materials to aid in the notification process.

- To help manage consent, Carespark has built a custom software solution, Master Patient Option Preference (MPOP), which allows providers to search by a patient-linked medical record number to see if a patient has opted out or has been notified.